End of Life Care
Current Awareness Bulletin
September 2020

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Title: Volunteers in palliative care: A healthcare system-wide cross-sectional survey.

Source: BMJ supportive & palliative care; Aug 2020
Author(s): Vanderstichelen, Steven; Cohen, Joachim; Van Wesemael, Yanna; Deliens, Luc; Chambaere, Kenneth

Objective: Volunteers are an important resource in bridging palliative care (PC) services and communities. However, no studies have systematically mapped volunteers' actual contributions to PC provision and how well they are supported by healthcare services at the volunteer level. Such insights are important to shape and optimise supportive environments for volunteering in PC. This study aimed to describe organised volunteering practices in PC across dedicated PC services and healthcare services providing generalist PC, in terms of tasks, training, supervision and how volunteers evaluate these.

Methods: A cross-sectional postal survey of 2273 volunteers from healthcare organisations providing care for people with serious illnesses in the Flemish healthcare system (Belgium) was conducted between June and November 2018. A two-step cluster randomised sample was used. Volunteers were recruited through their respective volunteering organisations.

Results: Response was obtained for 801 (35.2%) volunteers. Volunteers were predominantly women (75.5%), retired (70.8%) and aged 60-69 years (43.4%). Almost all volunteers provided psychosocial care (96.3%). Volunteers were found to provide either (1) broad volunteer support, emphasising psychosocial and existential care and signposting tasks or (2) narrow volunteer support, emphasising nursing care tasks. Nursing home volunteers had the lowest prevalence of PC training (7.7% vs 53.7% total, p<0.001).

Conclusions: Multidimensional support was most prevalent among dedicated PC volunteers, while practical support was most prevalent among sitting service volunteers. Results indicate that volunteers can offer complementary support for patients with serious illnesses, although this requires training and consistent supervision. This is currently suboptimal for volunteers in nursing homes and community home care.

Title: Palliative care delivery in residential aged care: bereaved family member experiences of the Supportive Hospice Aged Residential Exchange (SHARE) intervention.

Citation: BMC palliative care; Aug 2020; vol. 19 (no. 1); p. 127
Author(s): Frey, Rosemary; Barham, Sophia; Balmer, Deborah; Boyd, Michal; Robinson, Jackie; Gott, Merryn

Background: The supportive hospice aged residential exchange (SHARE) is a new model of palliative care education that has been designed for residential aged care. The goal of SHARE is to help clinical staff improve palliative care within residential aged care facilities and to improve specialist palliative care nurses' knowledge and skill to care for frail older people.

Method: The experiences of 18 bereaved families concerning the palliative care journey (both at the start and finish of a one-year implementation of SHARE) were explored using semi-structured interviews.

Results: Three themes were important to bereaved families' experience: communication with staff, systems of care, and hospice involvement. Sub-themes indicating changes in these three components of care between the start and finish of SHARE was identified. A
fourth theme highlighted challenges (relationship with GP, staff shortages, and turnover) that continued across SHARE.

**Conclusion:** Findings indicated that SHARE benefited families (improved communication and support) through the end of life journey of their relatives, but challenges remained.

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**Title:** Medication use in the last year of life: a cross-sectional hospice study.

**Citation:** BMJ supportive & palliative care; Aug 2020

**Author(s):** Scullion, Liam; Dodds, Hope; Liu, Qinghao; Hunt, Mary Elizabeth; Gordon, Simon; Todd, Adam

**Objectives:** The issue of polypharmacy and medication use in people with life limiting illness raises important questions from a clinical and ethical viewpoint. The objectives of our study were to (1) explore medication use among people with life limiting illness receiving hospice care; (2) apply consensus criteria to assess medication appropriateness; and (3) determine the overall pill burden in this patient population.

**Methods:** Six hospices in the North East of England were included. All deceased adult patients who received hospice care in 2018 were eligible for study inclusion. Descriptive statistics were used to report medication details; while medication appropriateness was assessed according to consensus criteria developed by Morin and colleagues.

**Results:** Six hundred and ninety patients were included in the study. Patients were using a mean number of 8.8 medications per day, while polypharmacy was evident in 80% of patients. In terms of potentially questionable medication, patients were prescribed a mean number of 1.3 per day. Common potentially questionable medications included vitamin and mineral supplements, antihypertensives, antiplatelets, lipid regulating agents and anticoagulants. The pill burden in this population was also high with, on average, people using 13.7 oral doses per day.

**Conclusions:** Polypharmacy is common in patients accessing hospice care, as is the use of potentially questionable medication. The pill burden in this patient population is also high, which may be an additional treatment burden to patients. Holistic deprescribing approaches for this population should be developed and implemented.

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**Title:** Discontinuation of Statins in Veterans Admitted to Nursing Homes near the End of Life.

**Citation:** Journal of the American Geriatrics Society; Aug 2020

**Author(s):** Thorpe, Carolyn T; Sileanu, Florentina E; Mor, Maria K; Zhao, Xinhua; Aspinall, Sherrrie; Ersek, Mary; Springer, Sydney; Niznik, Joshua D; Vu, Michelle; Schleiden, Loren J; Gellad, Walid F; Hunnicutt, Jacob; Thorpe, Joshua M; Hanlon, Joseph T

**Background/objectives:** Geriatric guidelines recommend against statin use in older adults with limited life expectancy (LLE) or advanced dementia (AD). This study examined resident and facility factors predicting statin discontinuation after nursing home (NH) admission in veterans with LLE/AD taking statins for secondary prevention.

**Design:** Retrospective cohort study of Veterans Affairs (VA) bar code medication administration records, Minimum Data Set (MDS) assessments, and utilization records linked to Medicare claims.

**Setting:** VA NHs, known as community living centers (CLCs).
Participants: Veterans aged 65 and older with coronary artery disease, stroke, or diabetes mellitus, type II, admitted in fiscal years 2009 to 2015, who met criteria for LLE/AD on their admission MDS and received statins in the week after admission (n = 13,110).

Measurements: Residents were followed until statin discontinuation (ie, gap in statin use ≥14 days), death, or censoring due to discharge, day 91 of the stay, or end of the study period. Competing risk models assessed cumulative incidence and predictors of discontinuation, stratified by whether the resident had their end-of-life (EOL) status designated or used hospice at admission.

Results: Overall cumulative incidence of statin discontinuation was 31% (95% confidence interval [CI] = 30%-32%) by day 91, and it was markedly higher in those with (52%; 95% CI = 50%-55%) vs without (25%; 95% CI = 24%-26%) EOL designation/hospice. In patients with EOL designation/hospice (n = 2,374), obesity, congestive heart failure, and admission from nonhospital settings predicted decreased likelihood of discontinuation; AD, dependency in activities of daily living, greater number of medications, and geographic region predicted increased likelihood of discontinuation. In patients without EOL designation/hospice (n = 10,736), older age and several specific markers of poor prognosis predicted greater discontinuation, whereas obesity/overweight predicted decreased discontinuation.

Conclusion: Most veterans with LLE/AD taking statins for secondary prevention do not discontinue statins following CLC admission. Designating residents as EOL status, hospice use, and individual clinical factors indicating poor prognosis may prompt deprescribing.

Title: Appointing nurses trained in organ donation to improve family consent rates

Citation: Nursing in Critical Care; Sep 2020; vol. 25 (no. 5); p. 299

Author(s): Witjes, Marloes; Jansen, Nichon E; Jacqueline van Dongen; Herold, Ingeborg H F; Otterspoor, Luuk; Bernadette J M Haase-Kromwijk; Johannes G van der Hoeven; Abdo, Wilson F

Background: One of the most important bottlenecks in the organ donation process worldwide is the high family refusal rate.

Aims and objectives: The main aim of this study was to examine whether family guidance by trained donation practitioners increased the family consent rate for organ donation.

Design: This was a prospective intervention study.

Methods: Intensive and coronary care unit nurses were trained in communication about donation (ie, trained donation practitioners) in two hospitals. The trained donation practitioners were appointed to guide the families of patients with a poor medical prognosis. When the patient became a potential donor, the trained donation practitioner was there to guide the family in making a well-considered decision about donation. We compared the family consent rate for donation with and without the guidance of a trained donation practitioner.

Results: The consent rate for donation with guidance by a trained donation practitioner was 58.8% (20/34), while the consent rate without guidance by a trained donation practitioner was 41.4% (41/99, P = 0.110) in those patients where the family had to decide on organ donation.

Conclusions: Our data suggest that family guidance by a trained donation practitioner could benefit consent rates for organ donation.

Relevance to clinical practice: Trained nurses play an important role in supporting the families of patients who became potential donors to guide them through the decision-making process after organ donation request.
Title: Deemed consent to organ donation: what critical care nurses need to know.

Citation: British Journal of Nursing; Aug 2020; vol. 29 (no. 15); p. 910-912
Author(s): Walton; Miller, Cathy; Maycock, Steven; Nicol, Kristian

Abstract: The article focuses on organ donation in England changed to a deemed consent system, which means adults who live and die in England are considered to be a donor after their death unless they have indicated that they did not want to be a donor. Topics include the organ donation has implemented after Wales has implemented a similar system in 2015, and the important that those working in critical care are fully aware of the important role and responsibility in understanding the new law.

Title: Implementing and improving the ReSPECT process within medical and orthopaedic departments of a district general hospital.

Citation: Progress in Palliative Care; Aug 2020; vol. 28 (no. 4); p. 254-259
Author(s): Misselbrook; Jackman, Daniel; Vora, Chintan; Briant-Evans, Toby; Wilkinson, Anna

Abstract: The Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) is a process supported by the Resuscitation Council (UK) and UK Royal Colleges to create personalized anticipatory care plans for patients. Hampshire Hospitals NHS Foundation Trust has been an early adopter of this process with variability in engagement with this process across our trust. A quality improvement project was performed to improvement engagement with ReSPECT as well as consistency and quality of documentation. Since patients admitted with fragility fractures are often frail, elderly and at risk of deterioration post-operatively, we focused on improving ReSPECT in the orthopaedic department with medical departments used for comparison post-intervention. Interventions included teaching sessions for consultants and junior doctors, increased senior orthogeriatrician input, and electronic documentation of ReSPECT forms. Post-intervention results revealed an improved engagement with the ReSPECT process with orthopaedic patients with frailty or life-limiting co-morbid conditions more likely to receive early anticipatory care planning as part of their admission process compared to medical inpatients. Senior consultant engagement was key to providing a cultural shift in early anticipatory care planning which helped to foster an environment of open communication among the team, allowing for more effective recognition of frail or co-morbid patients.

Title: An Interdisciplinary Framework for Palliative and Hospice Education and Practice

Citation: Journal of Holistic Nursing; Sep 2020; vol. 38 (no. 3); p. 320
Author(s): Dyess, Susan MacLeod; Prestia, Angela S; Levene, Richard; Gonzalez, Faustino

Abstract: Leading highly functional health care teams in all practice settings is sustained through the identification of a conceptual framework to guide education and practice. This article presents an interdisciplinary framework for palliative and hospice education and practice. The framework builds on theoretical caring to convey elements of relational, holistic and compassion; articulates interprofessional tenets for guiding values; and aligns with
constructs for palliative and hospice best practices. The framework invites those at the bedside and in leadership to be intentional in attending to education and the necessary activities that address the day-to-day operations of palliative and hospice care, as well as, honoring all interdisciplinary collaboration that supports quality outcomes and inspires actions that transform.

Title: Current status of organ donation after brain death in the UK.

Citation: Anaesthesia; Sep 2020; vol. 75 (no. 9); p. 1205-1214
Author(s): Manara, A R; Thomas, I

Abstract: Organ donation after brain death remains the deceased organ donation pathway of choice. In the UK, the current identification and referral rate for potential donation after brain death donors is 99%, the testing rate for determining death using neurological criteria is 86% and the approach to families for donation is 91%. Increasing donation after brain death donation will primarily require a large increase in the current consent rate of 72% to one matching the consent rate of 80-90% achieved in other European countries. Implementing the use of evidence-based donor optimisation bundles may increase the number of organs available for transplantation. Alternatively, the UK will need to look at more challenging ways of increasing the pool of potential donors after brain death. The first would be to delay the withdrawal of life-sustaining treatment in patients with devastating brain injury to allow progression to brain death after the family have given consent to organ donation and with their consent to this delay. Even more challenging would be the consideration of re-introducing intensive care to facilitate organ donation programmes that have been so successful at increasing the number of organ donors elsewhere.

Title: Hospice Staff Perspectives on Caring for People with Dementia: A Multisite, Multistakeholder Study.

Citation: Journal of Palliative Medicine; Aug 2020; vol. 23 (no. 8); p. 1013-1020
Author(s): Harrison ; Allison, Theresa A.; Garrett, Sarah B.; Thompson, Nicole; Sudore, Rebecca L.; Ritchie, Christine S.

Background: In the United States, 45% of people enrolled in hospice have dementia. We know little about how hospice professionals facilitate preference-aligned end-of-life care for people with dementia (PWD) and their families.
Objective: To examine hospice stakeholders' perspectives on caring for PWD and their families.
Design: Multisite qualitative study using semi-structured interviews with interdisciplinary hospice clinicians, leaders, and administrators. The interdisciplinary team used the constant comparative method to identify, code, and characterize relevant themes.
Setting/participants: Four geographically distinct nonprofit U.S. hospice organizations. Fifty-one hospice employees: 61% clinical staff, 25% executive leaders, and 14% administrators.
Measurements: Interview domains included participants' practices of engaging patients/families in discussions of preferences for end-of-life care and professional opinions of changes over time. Cross-topic probes focused on delivering hospice care to PWD and their proxies/families.
Results: Four themes regarding caring for PWD in hospice. (1) Dementia prevalence in hospice is increasing and some hospices are developing programs to accommodate specific needs. (2) Setting impacts discussions of preferences and care decisions. (3) Caring for PWD on hospice poses unique challenges caused by (i) perceptions that dementia is not terminal, (ii) a lack of advance care planning discussions before hospice admission, and (iii) proxy decision-makers who were inadequately prepared for their role. (4) Hospice regulatory and policy changes disproportionately impact PWD.

Conclusions: Hospice professionals perceive increasing demand for, and multilevel challenges to, caring for PWD. Clinicians "upstream" from hospice may help by engaging patients and proxies in discussions of preferences for end-of-life care and providing anticipatory guidance.

Title: Reflections on the integration of a narrative medicine and mindfulness program in hospice and palliative care.

Citation: Progress in Palliative Care; Aug 2020; vol. 28 (no. 4); p. 260-266
Author(s): Essary ; Lussier, Mark; Stone, Noah; Volk-Craft, Barbara; Hamilton, Gillian

Abstract: By 2060, almost 25% (98 million) of the population is expected to be aged 65 or older. Health care professionals who provide hospice and palliative care are overtasked and demonstrate symptoms of burnout. Narrative medicine and mindfulness interventions create meaningful connections with patients, improve the delivery of patient-centered care, and enhance the health of the caregivers. In this pilot program, health care professionals in hospice and palliative care settings were invited to participate in a study to evaluate the impact of narrative medicine or mindfulness on measures of burnout and empathy. Participants completed baseline and 12-week post-intervention surveys of burnout and empathy, as well as weekly journals of their experience. Mean overall scores for depersonalization were significantly reduced at 12-week post-intervention. There were no significant changes in emotional exhaustion or empathy compared to baseline. This brief, weekly intervention may be beneficial for both patients and health care professionals in the hospice and palliative care setting.

Title: Physical Activity in Hospice Care: A Social Ecological Perspective to Inform Policy and Practice.

Citation: Research quarterly for exercise and sport; Sep 2020; vol. 91 (no. 3); p. 500-513
Author(s): Burke, Shaunna; Utley, Andrea; Belchamber, Caroline; McDowall, Louise

Purpose: Physical activity (PA) is increasingly being used in hospice care as a rehabilitation strategy to help patients manage symptoms and improve quality of life. However, little is known about how to design and deliver interventions that promote uptake and maintenance of PA in this population. Single-level approaches (i.e., psychological models) have primarily been used to study factors that influence PA engagement among patients with advanced, incurable disease and therefore offer a limited perspective on strategies that target changes beyond the individual level. This study explored perspectives on factors perceived important for influencing PA participation in hospice care using a social-ecological framework.

Method: Patients (n = 27) and health providers (n = 5) from multiple hospices (n = 5) across the UK were involved in this study. Data were collected using focus group and individual semi-structured interviews and analyzed using a thematic framework approach.
**Results:** Eight main themes were perceived to be important for influencing PA engagement at the individual, interpersonal, physical environment, community, and policy levels including: (1) PA as therapy; (2) apprehension about PA-induced harm; (3) group-based PA with peers; (4) supervised PA sessions; (5) limited facilities and access; (6) patient-centered approach; (7) lack of a strong PA culture and; (8) absence of a policy and guidance for PA provision.

**Conclusion:** Hospice-based PA interventions that target multiple levels simultaneously may be more effective at successfully changing and sustaining patients’ PA behavior. Study findings provide evidence-based recommendations that may facilitate the effective delivery of PA interventions in hospice care.

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**Title:** Hospice Employees’ Perceptions of Their Work Environment: A Focus Group Perspective.

**Citation:** International journal of environmental research and public health; Aug 2020; vol. 17 (no. 17)

**Author(s):** Lehto, Rebecca H; Heeter, Carrie; Forman, Jeffrey; Shanafelt, Tait; Kamal, Arif; Miller, Patrick; Paletta, Michael

**Abstract:** Burnout in healthcare professionals can lead to adverse effects on physical and mental health, lower quality of care, and workforce shortages as employees leave the profession. Hospice professionals are thought to be at particularly high risk for burnout. The purpose of the study was to evaluate workplace perceptions of interdisciplinary hospice care workers who provide care to patients at end of life. Six focus groups and one semi-structured interview were conducted with mixed group of social workers, managers, nurses, hospice aides, chaplains, support staff, and a physician (n = 19). Findings from the groups depicted both rewards and challenges of hospice caregiving. Benefits included intrinsic satisfaction from the work, receiving positive patient and family feedback, and teamwork. Challenges reflected issues with workload, technology issues, administrative demands, travel-related problems, communication and interruptions, difficulties with taking time off from work and maintaining work-life integration, and coping with witnessing grief/loss. Hospice workers glean satisfaction from making meaningful differences in the lives of patients with terminal illness and their family members. It is an expected part of the job that certain patients and situations are particularly distressing; team support and targeted grief support is available for those times. Participants indicated that workload and administrative demands rather than dealing with death and dying were the biggest contributors to burnout. Participants reported episodic symptoms of burnout followed by deliberate steps to alleviate these symptoms. Notably, for all except one of the participants, burnout was cyclical. Symptoms would begin, they would take steps to deal with it (e.g., taking a mental health day), and they recovered. At an organizational level, a multipronged approach that includes both personal and occupational strategies is needed to support professional caregivers and help mitigate the stressors associated with hospice work.

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**Title:** Role of Physiotherapy in Hospice Care of Patients with Advanced Cancer: A Systematic Review.

**Citation:** The American journal of hospice & palliative care; Aug 2020 ; p. 1049909120951163

**Author(s):** Vira, Prina; Samuel, Stephen Rajan; Amaravadi, Sampath Kumar; Saxena, Pu Prakash; Rai Pv, Santosh; Kurian, Jestina Rachel; Gururaj, Rachita
Objective: To review the role of physiotherapy and its effects in hospice care of patients with advanced cancer.

Methods: A comprehensive literature search was performed in PubMed, Scopus, Web of Science, CINAHL and PEDro. The search strategy was devised, articles were screened, and 2 independent reviewers conducted data extraction. Eligible studies were methodologically assessed for quality rating using modified Downs and Black's checklist. The extracted data was summarized according to site/stage of cancer, details of intervention, outcome measures and the results.

Result: The total number of screened articles were 2102, out of which 9 were identified as suitable for the purposes of comprehensive review. The studies included exercise therapy, massage therapy, relaxation therapy, compression bandaging and use of TENS as the various physiotherapy interventions under consideration. Studies were generally of low to moderate quality. A broad range of outcomes were employed including physical symptoms like loss of function, pain, fatigue, edema, sleep disturbances and quality of life. The findings of the studies supported the benefits of the interventions.

Conclusion: A structured exercise protocol, massage therapy, TENS and compression bandaging are useful in alleviating the symptoms experienced by patients with advanced cancer in hospice care. The reduced symptom burden has reflected as an improvement in their quality of life. However, there is a further need for high quality studies to strengthen the findings of this review.

Title: Administration of label and off-label drugs by the subcutaneous route in palliative care: an observational cohort study.

Citation: BMJ supportive & palliative care; Sep 2020

Author(s): Jensen, Jesper Jørgen; Sjøgren, Per

Background: The marketing authorisation for many injectable drugs used in palliative care does not cover the frequently preferred subcutaneous route. Consequently, subcutaneous off-label drug administration is often practised.

Aim: To assess the use, safety and tolerability of subcutaneous label and subcutaneous off-label drug administration in a Danish hospice.

Material and methods: Retrospective data from hospice inpatient records registered with subcutaneous drug administration. Prospective data of subcutaneous drug administration registered to hospice inpatients over a period of 2 months.

Results: Drugs were administered subcutaneously to 90% of patients in both studied cohorts. Thirty different drugs were administered subcutaneously. Ten (33%) drugs were authorised for subcutaneous administration, 14 (47%) for intramuscular and 6 (20%) for intravenous administration only. A search in major palliative literature and scientific publications revealed that 11 of the 20 subcutaneous off-labelled drugs were administered with little to no support from these sources. In seven patients, 11 adverse drug reactions (ADRs) were registered. ADRs were all minor local reactions and led to drug discontinuation in two patients only.

Conclusion: Subcutaneous drug administration was frequently used in the hospice. Two-thirds of the drugs were administered subcutaneously off-label. The findings of only a few and minor ADRs indicate that the drugs identified in this study, although often subcutaneously off-label and with little support from palliative literature, were administered with acceptable safety and tolerability. Off-label treatment practised in the clinic should be identified, reported and serve as inspiration for future scientific research and incentives for extension of marketing authorisations.
Title: Interdisciplinary or Interprofessional: Why Terminology in Teamwork Matters to Hospice and Palliative Care.

Citation: Journal of palliative medicine; Sep 2020; vol. 23 (no. 9); p. 1157-1158

Author(s): Seaman, Jennifer B; Lakin, Joshua R; Anderson, Elizabeth; Bernacki, Rachelle; Candrian, Carey; Cotter, Valerie T; DeSanto-Madeya, Susan; Epstein, Andrew S; Kestenbaum, Allison; Izumi, Seiko; Sumser, Bridget; Tjia, Jennifer; Hurd, Caroline J

Title: Anticipatory prescribing in community end-of-life care in the UK and Ireland during the COVID-19 pandemic: online survey.

Citation: BMJ supportive & palliative care; Sep 2020; vol. 10 (no. 3); p. 343-349

Author(s): Antunes, Bárbara; Bowers, Ben; Winterburn, Isaac; Kelly, Michael P; Brodrick, Robert; Pollock, Kristian; Majumder, Megha; Spathis, Anna; Lawrie, Iain; George, Rob; Ryan, Richella; Barclay, Stephen

BACKGROUND: Anticipatory prescribing (AP) of injectable medications in advance of clinical need is established practice in community end-of-life care. Changes to prescribing guidelines and practice have been reported during the COVID-19 pandemic.

AIMS AND OBJECTIVES: To investigate UK and Ireland clinicians' experiences concerning changes in AP during the COVID-19 pandemic and their recommendations for change.

METHODS: Online survey of participants at previous AP national workshops, members of the Association for Palliative Medicine of Great Britain and Ireland and other professional organisations, with snowball sampling.

RESULTS: Two hundred and sixty-one replies were received between 9 and 19 April 2020 from clinicians in community, hospice and hospital settings across all areas of the UK and Ireland. Changes to AP local guidance and practice were reported: route of administration (47%), drugs prescribed (38%), total quantities prescribed (35%), doses and ranges (29%). Concerns over shortages of nurses and doctors to administer subcutaneous injections led 37% to consider drug administration by family or social caregivers, often by buccal, sublingual and transdermal routes. Clinical contact and patient assessment were more often remote via telephone or video (63%). Recommendations for regulatory changes to permit drug repurposing and easier community access were made.

CONCLUSIONS: The challenges of the COVID-19 pandemic for UK community palliative care has stimulated rapid innovation in AP. The extent to which these are implemented and their clinical efficacy need further examination.

Title: A Qualitative Study on the Experiences and Reflections of Junior Doctors During a Palliative Care Rotation: Perceptions of Challenges and Lessons Learnt.

Citation: Journal of pain and symptom management; Sep 2020; vol. 60 (no. 3); p. 549

Author(s): Choo Hwee, Poi; Hwee Sing, Khoo; Yong Hwang, Mervyn Koh; Hum Yin Mei, Allyn

Context: Doctors caring for patients with life-limiting illness are often exposed to emotional distress.
Objectives: We aimed to explore the experiences and perceptions of junior doctors working full time in a palliative care rotation. We examined the lessons junior doctors learnt in managing their emotions as they face patients' death on a daily basis.

Methods: We conducted a qualitative study with seven focus group discussions involving 21 junior doctors (medical officers and residents). Data were analyzed using qualitative thematic analysis to identify the themes related to the perceived challenges of these junior doctors and how they managed the struggles. Interviews were conducted with junior doctors who spent at least two months in a palliative care unit in a tertiary hospital or an inpatient hospice.

Results: Junior doctors caring for dying patients in a palliative care rotation faced internal conflicts. Conflicting feelings arose because of differing expectations from their preconceived notions of their roles as doctors. Two main themes of internal struggles were professional distancing and emotional detachment as well as prognostic uncertainty and when to withhold and withdraw medical treatments. Coping strategies that helped included mentoring and role modeling provided by palliative care physicians, reframing their care experiences and reflection to find meaning in their work.

Conclusion: A palliative care rotation exposes junior doctors to emotionally overwhelming experiences. With proper guidance, this exposure is useful in teaching junior doctors important coping strategies, allowing learning to occur at a deeper level.

Title: Caregiver-Reported Barriers to Quality End-of-Life Care in Dementia With Lewy Bodies: A Qualitative Analysis.

Citation: The American journal of hospice & palliative care; Sep 2020; vol. 37 (no. 9); p. 728-737

Author(s): Armstrong, Melissa J; Alliance, Slande; Corsentino, Pamela; Maixner, Susan M; Paulson, Henry L; Taylor, Angela

Objective: This study investigated barriers to quality end-of-life (EOL) care in the context of dementia with Lewy bodies (DLB), one of the most common degenerative dementias in the United States.

Methods: The study consisted of telephone interviews with caregivers and family members of individuals who died with DLB in the last 5 years. Interviews used a semi-structured questionnaire. Investigators employed a qualitative descriptive approach to analyze interview transcripts and identify common barriers to quality EOL care.

Results: Thirty participants completed interviews. Reported barriers to quality EOL experiences in DLB pertained to the DLB diagnosis itself and factors relating to the US health-care system, facilities, hospice, and health-care providers (physicians and staff). Commonly reported barriers included lack of recognition and knowledge of DLB, lack of education regarding what to expect, poor coordination of care and communication across health-care teams and circumstances, and difficulty accessing health-care resources including skilled nursing facility placement and hospice.

Conclusion: Many identified themes were consistent with published barriers to quality EOL care in dementia. However, DLB-specific EOL considerations included diagnostic challenges, lack of knowledge regarding DLB and resultant prescribing errors, difficulty accessing resources due to behavioral changes in DLB, and waiting to meet Medicare dementia hospice guidelines. Improving EOL experiences in DLB will require a multifaceted approach, starting with improving DLB recognition and provider knowledge. More research is needed to improve recognition of EOL in DLB and factors that drive quality EOL experiences.
Title: Virtual Reality Use for Symptom Management in Palliative Care: A Pilot Study to Assess User Perceptions.

Citation: Journal of palliative medicine; Sep 2020; vol. 23 (no. 9); p. 1233-1238

Author(s): Johnson, Tracy; Bauler, Laura; Vos, Duncan; Hifko, Alan; Garg, Paras; Ahmed, Mohammad; Raphelson, Michael

Abstract: In the past two decades, virtual reality (VR) technology has found use in a variety of clinical settings including pain management, physical medicine and rehabilitation, psychiatry, and neurology. However, little is known about the utility of VR in the palliative care setting. Moreover, previous investigations have not explored user perceptions of the VR experience in this population. Understanding user perceptions of the VR intervention will be critical for the development and delivery of effective VR therapies. To examine the utility of VR for palliative care patients, a pilot study of VR use was conducted with 12 adult patients diagnosed with life-limiting illness who were residents at a free-standing hospice facility. The intervention consisted of a one-time 30-minute VR experience. User perceptions were assessed through both quantitative and qualitative means, including participant responses to open-ended questions after the VR intervention. Acute changes in symptom burden were assessed using the revised Edmonton Symptom Assessment Scale. Participants found the VR experience to be both enjoyable and useful, and the intervention was well-tolerated overall. This study provides support for VR as a promising new therapeutic modality for patients undergoing palliative care.

Sources Used

The following databases are searched on a regular basis in the development of this bulletin:

British Nursing Index, Cinahl, Medline along with a number of other sources

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